FA Family Newsletter

#46 A Semi-annual Publication of the Fanconi Anemia Research Fund, Inc. Fall 2009

Adult FA Meeting Held in Denver

In July, the FA Research Fund hosted a three-day Adult FA Regional Meeting in Denver, Colorado. Fifteen adults with FA, along with nine family members and friends, attended the meeting. The adults with FA ranged in age from 19 to 47 and came from the US, Canada, and France. Nine of the adults had not previously attended a meeting sponsored by the Fund.

Over the course of three days, the adults heard presentations from top FA researchers and physicians, participated in support groups, went rafting down the Clear Creek River, and enjoyed unstructured time together. Physicians expert in FA presented

continued on page 14

FA adults enjoying rafting on the Clear Creek River

HIGHLIGHTS

The Hope of Induced Pluripotent Stem (iPS) Cells in FA

John Wagner, MD, University of Minnesota, described the 2008 discovery that embryo-like stem cells could be created from adult tissues as "the most significant breakthrough in a long time," when he spoke at our family meeting at Camp Sunshine. The defining characteristic of embryonic stem cells is two-fold: they can make exact copies of themselves and can also give rise to any tissue in the body. Induced pluripotent stem (iPS) cells have these same characteristics.

Researchers can create iPS cells from any tissue in the human body, such as skin cells. Using a viral delivery system, scientists introduce four genes into these cells. Over a period of five days, cells emerge which have all the characteristics of embryonic stem cells. These cells can be cultured to become any tissue of the body, such as bone marrow stem cells. This is particularly important for patients with FA who commonly develop marrow failure. Inserting a normal FA gene into iPS cells derived from the skin of FA patients means that these corrected cells could then be made into marrow cells.

The implications for future therapy are immense. IPS cells can become natural killer (NK) cells that kill cancer cells and can also become hematopoietic stem cells that can

continued on page 3

MEDICAL NEWS

Sally Kinsey, MD

Transplant Outcomes in the United Kingdom

Sally Kinsey, MD, St. James's University Hospital, Leeds, United Kingdom, described protocol considerations and outcomes of bone marrow transplantation in the UK from 1980-2008. During this time, eight centers have transplanted 70 patients ranging in age from 8 to 24. Approximately half of these patients had matched sibling donors; the others had either mismatched relative or unrelated donors.

The UK uses a non-radiation protocol for all transplants. Overall, 55 patients or 79% survived transplantation. However, prior to 2000, 68% survived; since 2000, 90% are survivors. Those who did not receive transfusions prior to transplant had better survival. Dr. Kinsey stated that the UK system uses coordinated management and a team approach among all transplant centers. ◆

New Directions in Unrelated Donor Transplants

The University of Minnesota Transplant Center has focused on FA transplants for almost two decades, and has made improved survival for this population a major goal.

All pediatric FA patients with matched sibling donors (18 patients) using the present non-irradiation protocol have survived with no GvHD. Unrelated donor transplants have presented a major challenge, however.

A series of unrelated donor transplant protocols implemented over the past decade has produced steadily improving outcomes. Twenty FA patients have now been transplanted using 300 rads of radiation and thymic shielding to hasten recovery of the immune system. Of this number, 89% survive. Although improved, GvHD and infection remain areas of concern.

Further improving survival while reducing toxicity and GvHD remain goals for an upcoming study. In approximately four months, Drs. John Wagner and Margaret MacMillan plan to eliminate use of prednisone and gradually reduce the time each patient takes cyclosporine post-transplant. They plan to add mesenchymal stem cells (MSC) post-transplant. MSC, which are found in the bone marrow and do not need to match the patient, are capable of suppressing GvHD, enhancing engraftment and possibly hastening tissue repair. If these cells are insufficient to prevent GvHD completely in FA patients, Wagner will introduce regulatory T-cells to the protocol, as these cells have been shown to induce tolerance between the donor and host in animal models. Importantly, regulatory T-cells are already in phase I trials to determine the optimal dose. "We keep hoping we'll get smarter," Wagner remarked. For many patients with unrelated donors, delaying the transplant has been worth it. With every change in the protocol, outcomes have improved. Based on the past track record, Wagner believes this trend will continue. ◆

John Wagner, MD

Parinda Mehta, MD

Transplant Outcomes in Cincinnati

Parinda Mehta, MD, Cincinnati Children's Hospital, gave an overview of the transplant process and updated Camp Sunshine attendees on transplant outcomes at her center. Thirty-five FA patients with matched sibling donors have undergone transplant in Cincinnati. Eighty-eight percent are alive and well ten years post-transplant. All patients transplanted with matched sibling donors during the past ten years survive. Thirty-two patients have undergone transplant with unrelated donors, using 450 rads of irradiation in the protocol. Twenty-five of 32 survive, or 78%. Cincinnati plans eventually to eliminate radiation as part of its unrelated donor protocol. ◆

Memorial Sloan-Kettering Transplant Results

by Farid Boulad, MD

Between 03/30/99 and 03/31/09, 24 patients with FA were transplanted at Memorial Sloan-Kettering using total body irradiation, fludarabine, and cyclophosphamide for cytoreduction, followed by a T-cell depleted bone marrow or peripheral blood stem cell transplant from alternative donors.

Patients were 14 males and 10 females, aged 5.5 to 35 years (median 12.6). Hematologic diagnoses and indications for transplant included aplastic anemia (n=11), myelodysplastic syndrome (n=6), and acute myeloid leukemia (n=7). Donors were matched unrelated (n=5), mismatched unrelated (n=11) or mismatched related (n=8). Risk factors included age >18 years in 6 patients; previous transfusions and previous use of androgens in 16 and 18 patients respectively; advanced hematologic disease in 13 patients, including 6 patients with chromosome 7 abnormalities; and mismatched donor transplants in 19 patients.

All 24 patients engrafted. Only two developed grade 2-4 graft vs. host disease (GvHD). Sixteen patients are alive and well, while 8 patients died from infections (n=2), relapse (n=2), GvHD (n=2), toxicity (n=1), and squamous cell carcinoma (n=1). ◆

Multi-center Transplantation Study Begins

by Farid Boulad, MD

Memorial Sloan-Kettering has begun a multi-center study of allogeneic stem cell transplantation for FA patients from alternative donors using a chemotherapy-only cytoreduction with busulfan instead of total body irradiation. Between April 2008 and July 2009, three patients received a busulfan-based cytoreduction, followed by a T-cell depleted transplant from unrelated or related mismatched donors. Two patients are alive and well. This study will include the following transplant centers: Boston Children's Hospital, Cincinnati Children's Hospital, Children's Hospital of Wisconsin, and Memorial Sloan-Kettering. ◆

The Hope of Induced Pluripotent Stem (iPS) Cells in FA

continued from page 1

repair the diseased marrow. There will no longer be a need for high doses of chemotherapy and allogeneic (coming from a donor) transplant, as the corrected cells are from the patient. It is envisioned that once the technique is perfected, patients will be treated shortly after diagnosis.

Dr. Wagner spoke of the many hurdles that remain to make these cells safe, and estimates that they will be ready for testing in the next 5–6 years. Working on these cells and getting them ready for clinical testing will be the primary focus of his team's work, starting now. ◆

FA: Guidelines for Diagnosis and Management Available

The Fund is happy to send additional copies of the newly published book, *Fanconi Anemia: Guidelines for Diagnosis and Management*, to families for their physicians, dentists, and other medical caregivers. To request copies, please e-mail info@fanconi.org or call our office at 541-687-4658 or 1-888-FANCONI. ◆

Complications after Bone Marrow Transplant

The success of bone marrow transplantation has improved fundamentally over the past 12 years with a series of new protocols to decrease toxicity and improve engraftment, according to Margy MacMillan, MD, University of Minnesota. Patients still have complications after transplantation related to the underlying diagnosis of FA and issues caused or exacerbated by the transplant itself.

During the first year after transplant, patients experience regimen-related toxicity, such as mouth sores and problems with the liver caused by chemotherapy and radiation. GvHD has decreased dramatically over these years, but 22% of patients with unrelated donors continue to experience this complication.

Chronic and acute GvHD are two completely different diseases. Chronic GvHD appears at least three months after transplant, takes weeks or months to develop, and is characterized by dry eyes, dry mouth, and occasionally severe lung dysfunction. It hastens development of cancer. Measures that eliminate GvHD cause infections and sometimes graft failure.

Patients are at high risk of infection for at least a year after transplant. Some FA patients have weak immune systems even before transplant and are especially prone to infections. Thymic shielding at the time of radiation has greatly reduced infection risk, yet infection remains a major problem.

Patients should wait at least a year before undergoing immunization; no live vaccine should be given until at least two years after transplant. The wait should be longer in the presence of chronic GvHD.

Are patients more likely to get mouth cancer after transplant? Dr. MacMillan noted that improved approaches to transplantation could make the risk of malignancy equal to that in non-transplanted patients. Of 169 patients transplanted in Minnesota, doctors are aware of only 3 cases of cancer.

Margy MacMillan, MD

With more patients living into adulthood, future care must include psychosocial counseling for the anxiety, depression and social withdrawal that can accompany managing this challenging and multi-faceted diagnosis. ◆

Scott Kozin, MD

Managing Hand and Arm Differences in FA

Scott Kozin, MD, Shriners Hospital for Children, Philadelphia, Pennsylvania, discussed the many complications involved in managing the hand and arm anomalies that often characterize FA patients. The reader is referred to Dr. Kozin's comprehensive article on this subject in the 2008 *Guidelines for Diagnosis and Management* book.

Most (70%) of the skeletal abnormalities that affect FA patients are in the upper extremities, primarily anomalies of the hand and forearm. The most common type of forearm anomaly is the absence of the radius and a thickened, shortened and bowed ulna. Treatment goals are to maximize length, improve appearance and function, and create a stable wrist. Doing nothing leads inevitably to a 90° angle between the hand and forearm.

Treatment of the arm involves stretching (which should start early and include frequent splint changes) and surgery. The goal of surgery, called centralization, is to place the wrist on the end of the ulna.

Unfortunately, achieving permanent correction is extremely difficult. Recurrence is common. Although one can often achieve improvement in appearance, improvement in function is often disappointing.

Thumbs can be small or absent. If there is no base for a thumb, a

continued on page 8

Head and Neck Cancer Presentation Clarifies Issues

Carter Van Waes, MD, PhD, Chief, Head & Neck Surgery Branch, NIH, spoke on the head and neck cancers that affect FA patients. He covered factors that contribute to these malignancies, suggestions for prevention, and current thoughts on treatment.

Factors that cause head and neck tumors in the general population are involved in FA cancers. These factors present an extraordinary risk to FA patients, due to their inability to repair damage to their DNA. The following can contribute to the development of head and neck cancer:

- Tobacco contains toxins that are extremely damaging to mouth tissues.
- Alcohol contains chemicals that can cause cancer and helps toxic chemicals get into the cells of the mouth.
- Injury from biting the tongue or sides of the mouth, scalding liquids, and poorly fitting dentures can cause damage to epithelial tissues of the mouth.
- Viruses such as the human papillomavirus (HPV) can cause cancer. HPV infection of the tonsil area and back of the throat is associated with the onset of sexual activity in the general population, specifically with oral sex.
- Radiation (including diagnostic x-rays).

Several precautions should be taken to decrease the risk of cancer:

- Avoid tobacco and alcohol.
- Prevent injury by maintaining good oral hygiene.
- Avoid scalding liquids, biting the sides of one's mouth or wearing ill-fitting braces.
- Obtain the HPV vaccine (males and females).
- Consult a physician knowledgeable about FA before undergoing diagnostic radiation.

Signs and symptoms of precancerous or cancerous mouth tissue include the following:

- Ulcers in the mouth that don't heal.
- Patches of white or white and red patches in the mouth that feel bumpy, not smooth, to the touch.
- A swollen gland (painful or painless) in the neck. A physician should examine the patient if the swollen gland lasts longer than two weeks and is not associated with a cold. If cold symptoms are present, an exam is warranted after a month.
- Bleeding in the mouth.
- Loose teeth, which can indicate cancer of the gums.
- Symptoms that affect only one side of the head (one stuffy ear, sinus pain, a visual change, one enlarged tonsil or pain in the tonsil area on one side), especially lasting longer than two weeks.
- Difficult or painful swallowing.
- Hoarseness that lasts two weeks without cold symptoms, persistent cough, bloody phlegm.

Early diagnosis should include self-examination of the mouth and neck once a month; dental care every 6-12 months; head and neck exam including endoscopy by an otolaryngologist once a year; and possibly an esophagoscopy to examine tissues below the voice box, including the esophagus.

At the present time, the most useful therapeutic approach for tumors discovered at an early stage is surgical removal. Chemotherapy and radiation can be extremely toxic to an FA patient, and should be done only at a center with expertise in FA.

Research today is focused on the use of compounds that might have a chemoprevention effect. Drugs such as Erbitux are presently in clinical trial at Johns Hopkins University. NIH researchers are planning a trial with a drug used for diabetes shown to shrink premalignant lesions in non-FA patients. Antioxidants in the diet might be helpful, but vitamin supplements can have undesired effects. An antioxidant drug called tempol prolonged the time before tumor development in FA mice. Dr. Van Waes believes that tempol will be available for clinical trials in the next year or two and that this drug might be helpful to FA patients.

For additional information on this subject the reader is referred to: www.nidcr.nih.gov/OralHealth/Topics/OralCancer/DetectingOralCancer.htm. Scroll down to "Oral Lesions Suspicious for Oral Cancer" to view precancerous and cancerous lesions. ◆

Carter Van Waes, MD, PhD

Eye Abnormalities in FA

by Ekaterini Tsilou, MD, National Eye Institute, NIH

Eye abnormalities are common in FA patients and may cause a variety of symptoms. They may be due to FA itself or may be a complication of bone marrow transplant (BMT).

The most common abnormality is small eyes that are otherwise normal, called "microphthalmia." When only the front part of the eye is small, the condition is "microcornea." Microcornea and microphthalmia usually cause no symptoms.

However, because of the tighter space, small eyes have a higher risk of developing a specific form of glaucoma, called "angle closure glaucoma." The presence of angle closure prevents drainage of the fluid inside the eye, leading to a buildup of pressure. If this is left untreated, it may lead to blindness. Symptoms of glaucoma include decreased vision, with headache, nausea and vomiting.

Other less frequent abnormalities are strabismus (crossed eyes), ptosis (droopy eyelids), epicanthal folds (eye folds near the bridge of the nose) and, rarely, retinal abnormalities, which can lead to a significant decrease in vision if left untreated. Ptosis might need to be corrected by surgery if the eyelids are low enough to obstruct the center of vision.

Dry eyes are the most frequent eye complication due to BMT. It is important to decrease this dry sensation and protect the eyes. Treatments commonly used are artificial tear drops and cyclosporine eye drops (Restasis). If drops do not work, the eye doctor can insert a punctal plug, which obstructs the tear drainage system and helps the eye remain moist.

Two complications may either be a direct effect of FA or a complication of the medications or radiation used during BMT. The first is cataract, or clouding of the lens of the eye. A cataract leads to decreased vision and glare with bright lights. It can be removed with surgery. However, FA patients have a higher risk of complications if their eyes are smaller than normal. The second complication is open angle glaucoma, which is increased pressure inside the eye despite an open drainage system. This can be treated with eye drops.

FA patients should see an eye doctor at least once a year, and more often if any of the above problems arise. ◆

Ekaterini Tsilou, MD

Heather Zierhut, MS

The Role of Genetics in FA

At the 2009 Adult FA Meeting, Heather Zierhut, MS, a genetic counselor from the University of Minnesota Medical Center, gave an interactive presentation on understanding the role of genetics in FA. In an effort to make the genetic concepts easier to understand, the group acted out the FA protein pathway, using FA protein balloons and chromosome streamers. Heather discussed why chromosomes, genes, and mutations are important for medical management as well as future research and treatment opportunities. She noted that FA patients are living longer and reviewed possible reasons for their increased age, such as milder mutations, mosaicism, androgens, and bone marrow transplant. Heather also discussed inheritance and reproduction as they pertain to the lives of adults with FA.

The University of Minnesota is currently interviewing FA adults and parents of children with FA to learn more about family experiences during the waiting period between receiving a diagnosis of FA and treatment with androgens or a bone marrow transplant. The purpose of the study is to learn what could be helpful during the waiting period. Contact Heather Zierhut, (telephone: 612-626-6743; e-mail hzierhu1@fairview.org) for more information. ◆

Erin Moaratty

Helping Patients Deal with Insurance and Financial Issues

Pat Jolley, RN, Supervisor of Patient Services and Erin Moaratty, Chief Special Projects Officer, from the Patient Advocate Foundation (PAF), spoke at the Adult FA Meeting and the Family Meeting respectively on the services PAF provides at no cost to patients with life-threatening or debilitating illnesses.

PAF case managers serve as liaisons between patients and their employers, creditors and/or insurers to resolve financial issues that relate to the diagnosis, including assuring access to care for the uninsured. Services include negotiating with providers on pre-authorization approvals, assisting with billing errors, and expediting the appeals process.

Case managers also work with patients to determine local, state and federal programs that provide assistance for individual needs, including Social Security Disability Insurance, Medicare, Medicaid, and State children's health insurance programs. Additionally, they can help negotiate access to pharmaceutical agents, chemotherapy and surgery to implant medical devices.

For additional information, contact the Patient Advocate Foundation toll free at 800-532-5274; e-mail help@patientadvocate.org; or visit its website at www.patientadvocate.org. ◆

Gynecological Issues Presented at FA Adult Meeting

by Pamela Stratton, MD, National Institute of Child Health and Human Development

Women with Fanconi anemia are prone to have a later menses and an early menopause. They often have a shortened reproductive life, and few over age 30 become pregnant. If women in their 20s have irregular periods, they should see a gynecologist to determine if they are entering menopause early.

Although women with FA may have decreased fertility, they can become pregnant and should use contraception when pregnancy is not desired. During pregnancy, they should be managed by a hematologist and a maternal fetal medicine specialist to help with any pregnancy-related complications.

Stem cell transplantation to treat Fanconi anemia can cause gynecologic abnormalities. Especially if a transplant occurs after puberty, ovarian function may be blunted, possibly affecting fertility as well as hormone production. Researchers are currently testing whether ovarian function can be protected by the use of a medication called lupron.

Because only bone marrow failure is corrected by a transplant, FA women will still be prone to cancer, especially those related to the human papillomavirus, like vulvar, vaginal and cervical, and head and neck cancer. Women with FA have an increased risk of cervical and vulvar cancer and at younger ages than other healthy women. They should undergo regular evaluations by a gynecologist to include cervical cytology screening, vulvar and vaginal inspection, and colposcopy and biopsy if any abnormal areas are noted or if the pap smear result is abnormal. Surgical treatment of any moderate or severe pre-cancer should be undertaken, with surveillance continuing after treatment.

Vaccination with the HPV vaccine may prevent some genital tract pre-cancer and cancer by preventing HPV infection, although the immune response to the vaccine has not been evaluated in FA patients. The HPV vaccine will not treat HPV disease that is already present. ◆

Pamela Stratton, MD

Endocrine Issues Discussed at FA Adult Meeting

by Anna Petryk, MD, University of Minnesota

Endocrine issues affect over 80% of individuals with FA. Endocrine function in FA adults has not been well described because published studies usually include children and only a few adults. The most common endocrine abnormalities include low thyroid hormone levels (hypothyroidism), short stature with or without growth hormone deficiency, abnormal gonadal function, low bone mineral density (osteopenia/osteoporosis), lipid abnormalities, and abnormal glucose and insulin metabolism (lower than expected insulin secretion or reduced sensitivity to insulin). Hypothyroidism and gonadal dysfunction can be treated with synthetic hormones.

Possible causes of endocrine disorders include chronic red cell transfusion that may lead to iron deposition in endocrine glands, androgen therapy, midline brain abnormalities, and an underlying genetic abnormality. Some endocrine problems are more common after hematopoietic cell transplantation.

Anna Petryk, MD

To ameliorate bone loss, preventive measures can be taken, such as adequate calcium and vitamin D intake, weightbearing exercise, and adequate hormonal replacement. To ameliorate insulin abnormalities, concentrated sweets and excessive sugar intake can be avoided. Endocrine abnormalities are not always obvious from looking at a person; thus, a full endocrine evaluation tailored to patients with FA is very important. ◆

Managing Hand and Arm Differences in FA

continued from page 4

thumb can be created by moving the index finger to the thumb position. This surgical procedure is called pollicization. Unlike centralization, pollicization is often very successful and can improve function.

Children begin to use a thumb-index pinch motion at about one year of age, so pollicization is often performed at about that time to maximize function, although it can be done at any age. Success depends in part on the flexibility of the index finger. A stiff index finger may result in a gross grasp but not a fine pinch. A mobile index produces a better thumb that is incorporated into grasp and pinch.

Pollicization is an extremely complicated surgical procedure and is done in only a few centers in the country. It is best done by an orthopedic hand surgeon specializing in pediatrics. Dr. Kozin performs 12–15 of these procedures annually, which is considered a high number. ◆

Bev Mayhew Hired as Executive Director

The Board of Directors of the FA Research Fund is delighted to announce that Beverly Mayhew has been hired as Executive Director, succeeding Jeanne Negley, who resigned in July.

Bev brings extensive experience to the Fund, having served for the last nine years as a vice-president of The Ulum Group in Eugene, a public relations and marketing firm. Prior to that, she served for ten years as the Director of Public Affairs and Communication for PeaceHealth, a regional health care organization which included a 432-bed hospital. Earlier, she was Director of Programs and Communications for Citizens Energy Corporation, Boston. She has a Masters of Business Administration and a Master of Public Administration and has served on the board of directors of numerous community organizations in Eugene. She can be reached at the Fund and by e-mail at bev@fanconi.org. ◆

Bev Mayhew

FAMILY NEWS

Our Son, Our Hero

by Michael and Katharine Ormond

Elias Ormond

We always describe our son Elias as an ordinary boy with extraordinary faith, heart, and desire who has a resilience that few people know. Born in May 2008, his first sixteen months saw more days in a hospital than at home. Elias is the personification of medically complex. He has battled for his life several times, enduring more than two dozen operations including six hours of life-saving surgery, when he was less than 36 hours old. At just two and a half months of age, Elias had surgery to place a tracheostomy and gastrostomy. He almost passed away because his doctors were not aware he had pneumonia and the stress of the surgery was too much. We have watched him overcome challenges and adversity so many times. That is when we found that elite group of fighting spirits and winning attitudes to which Elias belongs, the children and adults with Fanconi anemia.

We received confirmation of his FA diagnosis on October 9, 2008, just one day after celebrating our third wedding anniversary. We were discharged from the NICU six days later after five and a half long, emotional months. We were frightened enough having Elias at home in his medically fragile state. Now we were learning a new diagnosis, one that did not always have a positive outcome. We were not home but a few days before the hospitalization cycles we have come to accept and know began.

Through all of this, Elias remains a positive force and a lovable child who immediately captures people's hearts. He is playful and never seems to get frustrated by his limits, but rather adapts and compensates very quickly. For example, Elias is missing the radii bone in both arms and has absent thumbs, with a clubbed wrist in both hands. He amazes us everyday with the things he can do that you would not expect. His determination is inspiring.

We began to realize that Elias deserved and needed a higher level of care and sought out the FA Comprehensive Clinic at Cincinnati Children's Hospital Medical Center. We eagerly made the sacrifice to move to Cincinnati for the sole purpose of Elias and his medical needs. We have had no regrets, as our move has already yielded new findings and changes we may have not learned until it was too late.

We know that whatever Elias' outcome with FA may be, he will put up an amazing fight to get to that point. We continue to look at everyday as a gift and embrace the moments we get as a family, be it in a hospital room or in our home. We cherish the smile he gives us every day when he truly has the right to frown. We are very proud of Elias and are proud to be his parents.

There are so many things about FA worthy of hate. In recent months, we have seen the passing of several brave, strong, inspiring children. However, Elias reminds us every day of the things worth loving. We would like to leave you with a quote by the man for whom we named Elias, Walter Elias Disney: "Happiness is what you make of it; it's all in how you look at things."

We invite you to follow Elias at http://mycarouselofprogress.blogspot.com. ◆

The Mefford Family

by Stacey Mefford

The Mefford Family

Our son Connor was diagnosed with FA on Friday, April 10, 2009. I received a phone call from the nurse of our local hematologist, who said that the doctor wanted to see us first thing on Monday morning. Earlier Connor had a bone marrow biopsy which had ruled out leukemia. I asked the nurse if he had FA. She said, "I can't tell you that," but after I persisted, she eventually delivered the news to me. I had been told six months earlier that Connor did not have FA, so I was devastated.

Since then we had our other two kids tested. Our daughter Bailey, who is six, does not have FA. Unfortunately, our new baby boy, Dane, does. He is now six months old.

Connor is a very happy, active child who does not look like he could have such a devastating disease. His blood counts, though, tell a different story. So far, Dane's counts are normal, and he is the happiest baby I have ever seen.

Never in my life did I imagine that we would be in this position. When Jeremy and I got married, we had dreams of a healthy family. We wanted to have children and be able to do many fun things with them,

continued on page 11

"A Dream is a Wish Your Heart Makes"

by Natalie Curry

My family and I recently celebrated a milestone: the twentieth anniversary of my cord blood transplant for Fanconi anemia. In 1989, transplants of this kind were extremely revolutionary; in fact, mine was one of the first. I have learned a lot over the past twenty years: about all the sacrifices my family had to make, all the battles that we fought, and all the tears that we shed. Recently, my mother said that she was never afraid to dream for me, but that she was only afraid I would never be able to dream for myself. Here I am, age 24, after a successful cord blood transplant, kidney transplant, and countless other procedures, dreaming dreams and making them come true.

One year ago I took a giant step and moved from my small town in Indiana to New York City with my two sisters, Audrey and Emily. I didn't know exactly what the city would have in store for me, but I knew that it was where my heart wanted me to be. I have had some of the most wonderful experiences of my life here. I got to see the Rockettes during the holidays, took an acting class in Times Square, ate Valentine's Day dinner at the Waldorf Astoria, watched the inflation of the Macy's Thanksgiving Day Parade balloons, walked in Central Park, and watched the leaves change and then fall. I am so grateful for having had these opportunities.

Natalie Curry and Justin Palma

I have always had a burning passion to help others, but was never sure how. Shortly after I arrived in

continued on page 24

Our Journey with Fanconi Anemia

by Tricia Mitchell

We are a proud military family. My husband and I have had the privilege of living overseas for most of his career in the army. We were living in Okinawa, Japan in 2008 when our beautiful little Emily was born. My husband missed Emily's birth by one day. He was in Washington State for work, and it took four long days to bring him home.

Emily was so tiny! She weighed 3 pounds, 1 ounce, and was only 15 inches long. She was smaller than her big sister's baby doll. Emily's doctors kept coming to my room with bad news. She was missing her left thumb, had a horseshoe kidney, had a heart murmur, small optic nerves, and was very anemic. She ended up having a blood transfusion after hemorrhaging from her umbilical cord. My poor baby was hooked up to so many machines.

The Mitchell Family

Emily just would not gain weight and grow. Our doctors were very concerned. They were going to wait for a few days and then send her to Hawaii so Emily could have a permanent feeding tube. However, a little miracle happened over the weekend, and Emily began to grow. It took weeks for her to get off her oxygen and even longer to get rid of her feeding tube.

continued on page 15

The Mefford Family

continued from page 10

including sports, vacations, and everything that comes with having children. So, to be in this position is very difficult for us. When we received the diagnoses of FA, our dreams, expectations, and lives were forever changed.

We are very helpless at this point, feeling that there is nothing we can do for the boys. That is so hard on a mother and a father who are supposed to be able to do anything to help their children. But, we have decided to fight back by helping to find a cure for this terrible disease. The only way that we can do that is by raising funds for FA research.

We recently went to Camp Sunshine. It was awesome for us to meet all of those incredible people and a special honor to meet some of the researchers who are trying to save our kids' lives. Our boys had a blast, and we learned a lot. The most important thing we received is hope that our boys will have a future. We are currently working on a fundraising letter and are beginning our journey to start raising money and help to find a cure for FA.

Connor's web site is www.caringbridge.org/visit/connormefford. ◆

Editors' Note and Disclaimer

Statements and opinions expressed in this newsletter are those of the authors and not necessarily those of the editors or the Fanconi Anemia Research Fund. Information provided in this newsletter about medications, treatments or products should not be construed as medical instruction or scientific endorsement. *Always consult your physician before taking any action based on this information.*

Enjoying the 2009 Family Meeting at Camp Sunshine

Amitai performing at the Talent Show

Annual FA Family Meeting

The 18th Annual Family Meeting was held at Camp Sunshine in Casco, Maine this past August. Fifty-nine families attended, from the United States, Canada, Argentina, Australia, France, Germany, Israel, and the United Kingdom. Of those, thirteen families attended the Family Meeting for the first time. In all, fifty-three children with FA attended. Best of all, thirteen adults with FA, ages 18–55, participated in the meeting, giving families a new sense of hope.

Over the course of four days, researchers and physicians from the United States, the United Kingdom, and Germany presented invaluable information to families about FA treatments and cancer screenings. The children enjoyed many activities, including arts and crafts, baking, singing, playing games, boating, fishing, and swimming. They made

Setting wishboats afloat

Nicholas preparing for the Balloon Release

"It was wonderful. I am so grateful to have been able to attend."

"This has been such a gift to our family, and we thank you."

"A very hopeful camp."

"We hope that we can come again next year."

"The presentation topics were excellent!"

"The location was perfect, the weather was awesome, and the lake was beautiful."

wishboats, decorated them beautifully, and then sailed them in the pond. Families wrote messages of love, memories, and hope on white balloons for the annual memorial balloon release. Children and adults alike dressed up in costumes for the masquerade ball and danced the night away. The talents of the children were revealed and enjoyed by all during the talent show. Not to be outdone, the parents and adults with FA enjoyed themselves during the banquet and gave their all in karaoke performances.

Once again, the Camp Sunshine staff and volunteers showed their dedication, love, and support to our families. Families reported feeling a sense of hope when Camp came to a close. They shed tears as they said good-bye, and promised to stay in touch. ◆

Patients, siblings, and volunteers enjoying a marshmallow roast

A Look at the 2009 Adult FA Meeting

Adult FA Meeting Held in Denver

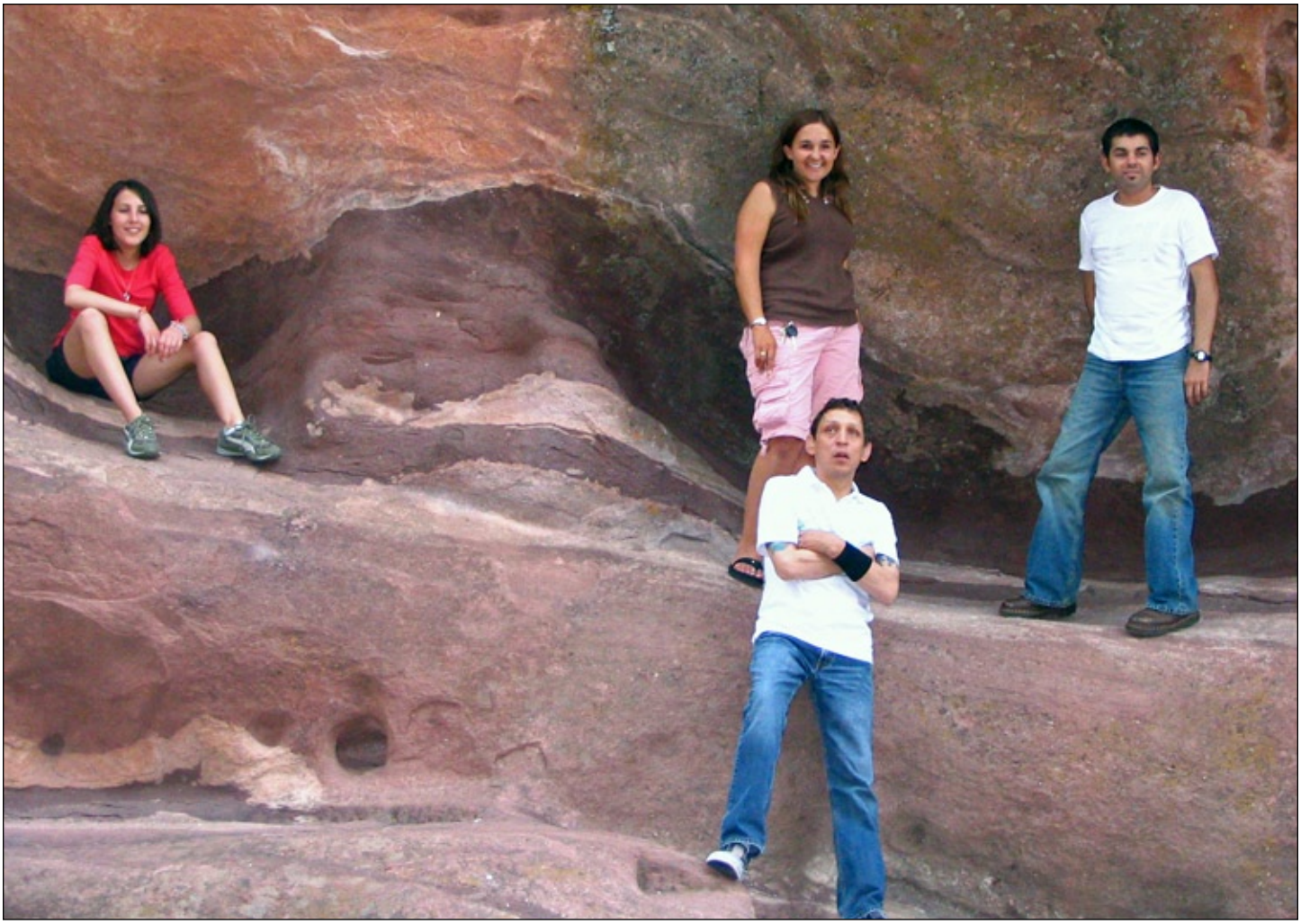
continued from page 1

information on cancer epidemiology, squamous cell carcinoma, and gynecologic and endocrine issues. Other presentations included the role of genetics, an overview of the Patient Advocate Foundation, the importance of donating tissue samples to the National Disease Research Interchange for research purposes, and fundraising for FA research.

Prior to the meeting, many of the adults had not met another adult with Fanconi anemia, while others were excited to see old friends and familiar faces. All left the meeting with a greater understanding of FA, knowledge of the importance of regular cancer screenings, a connection with other adults who are living and coping with FA, and great enthusiasm for another meeting for adults in the future. ◆

New friends: Marcia and Luella

Adult patients of all ages attended the meeting



Kim, Alissa, Justin, and Graham (bottom) explore Red Rocks Amphitheatre, one of the attractions near Denver.

"Expectations of the meeting were exceeded."

"I needed to meet others and the bond was instant!"

"Rafting was a blast!"

"The speakers did an amazing job of offering to go the extra mile to find out answers to my questions."

"I was excited about meeting other adults with FA…this has been an amazing time!"

"In a word: AWESOME!"

Our Journey with Fanconi Anemia

continued from page 11

When Emily was four weeks old, her doctor sat us down and opened a large medical book. He looked at us, pointed to a picture, and told us he thought Emily had Fanconi anemia. He explained what it was and, in an instant, our lives were changed forever. We were devastated. I held Emily that night and cried. She looked so healthy. Sure, she was tiny and pale, but she was so active and beautiful.

My husband and I went online and started doing research. We wanted to know as much as we could because our doctors really didn't know a lot about FA. We moved to Hawaii when Emily was three months old and received confirmation there that she did, in fact, have FA. We then tested her big sister, Erin, and found out that she does not have FA.

We had the opportunity to go to Camp Sunshine last month. It was one of the most memorable weeks of my life. I met so many wonderful families and learned so much about FA. It completely empowered me! I now have so much hope for Emily. I no longer cry when I feed her at night. Now I rock her and smile because my baby has a challenging, but bright, future ahead. ◆

A Mother's Experience at the FA Adult Meeting

by Julie Barbier

My family's journey with Fanconi anemia had always centered on children. Upon Justin's diagnosis at the age of 16, we were told that FA was a pediatric disease and that our son would not live past his teens. Through diligent research and determination, we located Dr. John Wagner at the University of Minnesota, who gave us our first glimmer of hope by greeting Justin with, "Justin, we can save your life. It is doable and *we* can do it."

Six years later, at the age of 22, Justin's annual bone marrow aspiration revealed pre-cancerous changes. A donor search began, and by July 2007 we were headed to Minneapolis to begin our bone marrow transplant journey. Justin was asked to participate in a transplant protocol that used a lower dose of total body irradiation. Unfortunately, the transplant failed; however, his donor agreed to donate additional marrow for a second transplant in December 2007. Throughout our ten-month stay in Minnesota, we met many exceptional FA children and their families.

When the invitation came to attend the Adult FA Conference in Denver, we had conflicted feelings. Although it would be amazing to meet other adults living with FA, we worried about the unknown. Nonetheless, we chose to attend. The location, speakers and amenities added to an exceptional weekend. From the first moment they were introduced, this group of adults bonded and chose to spend their extra time getting to know one another. From a late night pool party to early morning games and talks in the lobby, they found support in one another. They embraced their similarities and accepted their differences.

FA moms Carol Ybarra, Pat Burk, Julie Barbier, and Nancy Driver

As a mother, I cherish the time spent exchanging information with the other mothers present. We laughed, cried, and rejoiced to have finally met others who met and conquered the challenges of raising a FA child into adulthood. We understood the worries associated with adult lifestyle choices (smoking, drinking, etc.) that can endanger their fragile lives, with the knowledge that we no longer control their destinies. We exchanged contact information to remain in touch once we left Colorado. I consider it a blessing to have met so many strong, determined women who overcame obstacles in getting their children the care they needed in a medical world that didn't understand them. We had all heard the same grim prognosis, yet met the challenge head-on. We shared a strong commitment to raising resilient FA children into independent FA adults. The proof that we succeeded was present at this conference in Denver.

As research progresses, my prayer is for all FA children to join the ranks of this elite group. I left the weekend with a feeling that Justin had found what was missing in his life as he copes with living with FA. He had found acceptance and others who understood. ◆

Use of Logo

A reminder to our FA families: please use our logo or letterhead only after you have consulted the staff of the FA Research Fund and received their approval. This step is necessary to be sure our messages are accurate and consistent and helps to avoid legal complications. We are happy to collaborate on fundraisers and mailings.

International FA Family Meetings

The Fund is pleased to report that FA family support groups in the UK, Australia, France and Germany have sponsored meetings in recent months.

UK Fanconi Anemia Family/ Clinicians Meeting:

Bob Dalgleish, Secretary for the Fanconi Hope Charitable Trust, reported that the Trust sponsored the first Family and Clinicians Meeting from September 18–19 on the grounds of Chatsworth House, the ancestral home of their patron, the Duchess of Devonshire. The first day's meeting was held in the farmyard/adventure playground, which was perfect for entertaining the children and providing an informal setting for the meeting.

Sixteen families attended, and the patients ranged in age from 3–23. Additionally, UK clinicians and invited speakers from Germany and Spain attended. Bob reported that the evaluations of the meeting were outstanding and that the group is "grateful for all the support and inspiration provide by the FARF which has allowed us to make such encouraging progress here in the UK in a relatively short time." For additional information on the services provided by Fanconi Hope, visit www.fanconihope.org.

1st German/French Adult FA Meeting:

FA adult Christophe Bichet, as an FA representative from France, hosted seven members of a German support group (www.fanconi.de) in March near Fontainebleau. Ralf Dietrich and Eunike Velleuer, MD, attended with seven FA adults from Germany. The goal of the meeting was to allow FA adults to meet one another and to share their experiences in coping with FA. Christophe reports that "this initiative was a real success!"

Australia Fanconi Camp 2009:

Alan Howard-Jones, Fanconi Anaemia Australia Ltd, reported that the second annual Fanconi camp was held in early September at Woodhouse Activity Centre in Adelaide Hills, South Australia. Twenty-five FA parents, kids, adults, siblings and friends attended. The program focused on relaxation with free time for all to get to know one another in the picturesque surroundings. Activities included an obstacle course, nature walks, arts and crafts, and loads of fun activities for the kids, including a grand talent night on the final evening. Dr. Tom Revesz, Adelaide Children's Hospital's Haematology/Oncology Unit, spoke with the adults and parents, which was much appreciated. For more information, visit www.fanconicamp.org.au.

Upcoming International Fanconi Anemia Meetings:

October 30, 2009: 2nd German FA Family Weekend. For more information visit www.fanconi.de.

November 11, 2009: Brazilian FA Family Meeting. Contact Carmem Bonfim, MD, at carmem_bonfim@terra.com.br.

November 26–27, 2009: 5th Annual Spanish Fanconi Anemia Symposium. Contact Jordi Surralles, PhD, at jordi.surralles@uab.es. ◆

The Duchess of Devonshire with Trustees of the UK and Irish FA Group

FA adults Stacy, Kelly and Charisse at the Australian Family Meeting

FUNDRAISING

Run4Fanconi 5K Run/Walk

by Kerrie Brannock

Every year for the past five years, Jason's father and I have sent a fundraising letter to family and friends with an update on the progress of our son, Jason, and a plea for donations to the Fanconi Anemia Research Fund. I would encourage everyone to write letters. People you know want to help YOUR child and YOUR family, and a letter shares the personal impact of Fanconi anemia and personalizes the need for a cure. The earliest letters right after Jason's bone marrow transplant had the best response, as Jason was obviously very sick. However, as time has gone by and Jason's health has improved, it's been increasingly challenging to communicate the same sense of urgency— such as the risk of squamous cell carcinoma—as was obvious then when his bone marrow was failing. I felt that my fundraising efforts needed to expand beyond family and friends, even though I had no idea where to start.

My friend, Mauro Cazzari, suggested a 5K (Run4Fanconi, www.run4fanconi.org) to raise money for FARF. This initially sounded overwhelming. Neither of us had ever even participated in a run! The challenges seemed too many, from putting together a web site, getting the proper permits, advertising, getting t-shirts, recruiting volunteers, and finding sponsors. With each other's encouragement and with the help of some friends (including FA parent Peg Padden), we took one step at a time, learning things as we went. We'd particularly like to thank the FA family of Carter Pepper for joining us in this fundraising adventure without hesitation and for providing a tremendous amount of help. What kept us going was keeping our eye on the goal of raising awareness and funds for FA research to find a cure for Jason and others. In our hearts and minds, this one event didn't have to make thousands—it just had to be a stepping stone to get us closer to our goal. We hoped we could build on this first race in years to come.

Despite some concern that we might not have enough participants, over 100 people signed up and we raised $6,000! A relative's lacrosse coach learned of the race and had the whole high school lacrosse team sign up! Family members came from all over the country (even Hawaii) to help out. It was truly amazing to see all the support the event received. Everyone seemed eager to help and to learn about Fanconi anemia. Many people encouraged us to repeat the event next year.

We learned from this experience that we can't let our inhibitions about asking for money or our fears that it will be too difficult stop us from fundraising. We just have to do it, because if we don't raise the money for research to help save our kids, no one else will. If you're thinking about organizing a run, we'd love to help you with ideas and materials. Thanks largely to FARF-funded research, we have made tremendous progress, from transplants to the exciting promise of iPS cells. All of our fundraising efforts, now more than ever, can bring great hope for our FA patients. ◆

Jason Brannock (front right) and other runners at the 5K

Climbing Mount Washington for FA Research

by Tanner Lindsay

Early on the morning of August 10, I got up around 4 a.m., not sure what I had gotten myself into. The week before, we had been to the top of Cadillac Mountain in Maine, at a summit of around 1,500 feet. Thinking about the 4,000 feet plus I was about to climb had me quite worried, since I have never before hiked. Doubts crossed my mind, but I figured I would do my best.

As we pulled up to the mountain, there was no top in sight. It was obscured by the clouds. We hiked all morning, stopping for a few breaks, and saw nature at its finest, untouched and lush, with several streams and waterfalls. The temperature was 63°F at the base, but we were completely drenched in sweat within the first 30 minutes. The grade was fairly steep and steady for about the first two miles. After that, we started a much steeper climb, flanked by a stream and a waterfall. We passed by an old well still in use for drinking water. I could not resist pumping some out like I did when I was a kid. It was some of the coldest water I have had.

As we ascended past the cloud line, the terrain was steeper and damp, with endless boulders to climb through and over. Cloud cover was thick, with probably 50 yards of visibility. As we neared the summit, the distance seemed to grow, as our hiking had turned more into climbing. At this point, the temperatures were probably dipping into the 40s and the winds were 20-30 mph. Finally we reached the summit, where there was a rest area with hot food and drinks. When we stood by the summit sign, it was very difficult to stand still for the photo, as it was very cold and the wind felt like 60–70 mph.

My son, Baylor, had a successful unrelated donor bone marrow transplant on February 20, 2008. He never once complained about what he had to

continued on page 23

Climbers at the summit of the mountain

Fundraising Assistance

Did you know that 85 percent of the donations to the FA Research Fund are raised by FA families? Obviously, we need the efforts of everyone who reads this newsletter!

FA Family Fundraising Teams now exist on a regional level to assist our families with fundraising. If you are unsure how to contact your team leader, contact the FA Research Fund.

The staff of the Fund is ready to assist you with your fundraising efforts. We'll help you write or edit your fundraising letter; photocopy it; provide the postage; and mail it from our office, using your mailing list. If you're going to hold a fundraising event, we'll provide similar help.

The FA Research Fund asks FA parents to make certain that any event they hold is covered by liability insurance. Insurance for a one-time event is often available through a rider on the family's homeowners insurance policy or through "special events" insurance, both relatively inexpensive. Please contact the Fund if you need assistance obtaining or paying for this required insurance.

Please ask your donors to write their donation check to the "Fanconi Anemia Research Fund." When a donation is received, we will generate a letter of thanks from the Fund with a tax receipt, and we'll notify you that a donation has been made in your name.

Our sincere thanks to all of you for your efforts to raise funds to combat this devastating disease.

Caddy for a Cure

by Russ Holden

When I saw that baby car carrier, I did not want to look. After all, I had two healthy children at the time, and I did not think that I could handle emotionally looking at this child who was born with serious birth defects. But, beyond my control, it was going to happen. Susan Collins swept into my office with weeks old Christian, placed him on my desk and, in a whirlwind, began to unwrap the many blankets surrounding the baby.

I was stunned. I had never seen a more innocent child. He was beautiful. He was so small. As he lay there and cried, and I held him in my arms, my heart and my life were changed forever. How could this happen to someone so innocent? How unfair was it that I should be blessed with two healthy boys?

Seeing beautiful Christian ignited a passion in my heart that has known no boundaries. I did not know how or where or what I was going to do. I just knew I had to do something that would raise awareness and funds for Fanconi anemia. My life would not be complete unless I did.

Helping Christian and other FA patients took over our family's hearts and minds and was the impetus behind the creation of Caddy for a Cure, a highly successful initiative on the PGA TOUR that has touched the lives of many and has raised funds for and awareness of FA. Christian is now 16 years old and the national spokesperson for Caddy for a Cure. ◆

Russ Holden and Caddy for a Cure spokesperson Christian Collins

Upcoming Fundraisers for FA Research

2009

October 22, 2009: Play for FA Golf Tournament, Midlothian, VA. Independence Golf Course. For more information, visit www.playforfa.org or contact Lorraine McQueen at lmqueen01@verizon.net or (804) 247-1459.

November 21, 2009: Hoot 'N' Holler, Denver, CO. Dinner, dancing, auction, Texas Hold 'em. Hilton Garden Inn Denver Tech Center. Contact Jeanne Atkinson at (303) 349-1309 or jeanne@katafoundation.org or Lisa Nash at (303) 773-6228 or nashjlcolo@aol.com.

2010

February 14: 6th Annual Valentine FA 5K Run/Walk, Portland, OR. Contact: Peg Padden at pegpadpad@hotmail.com.

June 26: 6th Annual Coley's Cause Golf Tournament, Lakeville, MA. Poquoy Brook Country Club. For more information, visit www.coleyscause.com.

Ongoing:

Kaps for Kendall: In memory of Kendall Atkinson, donate to the Fund by sponsoring a volunteer to knit hats for children and adults who lose their hair to chemotherapy and radiation. Contact: Allison and Whitney Atkinson at www.kapsforkendall.org.

CaddyForACure: This organization generates charitable funds for designated nonprofits while offering the opportunity to be "inside the ropes" as a caddy for a Tour player at a PGA Tour event. This perfect gift for a golf fanatic offers a one-of-a-kind professional sports fantasy while contributing to genetic disease research. A portion of the proceeds from Caddy for a Cure is donated to the Fanconi Anemia Research Fund. Contact Russ Holden at www.CaddyForACure.com.

Sandy Carter Photography: Online shop donates 100% of sales to FARF. Visit www.sandycarterphoto.etsy.com or contact Sandy Carter at sc-photo@comcast.net for more information.

Your FA Research Dollars at Work in 2009

In 2009 thus far, the Fanconi Anemia Research Fund has awarded $1,234,007 in research grants to the following projects:

Investigator:	Grover Bagby, Jr., MD, Oregon Health & Science University, Portland, Oregon
Title:	Preclinical Evaluation of Small Molecules as Potential Therapeutic Agents in Fanconi Anemia
Amount:	$49,000
Investigator:	Philip Connell, MD, University of Chicago, Chicago, Illinois
Title:	Restoration of Homologous Recombination in Fanconi Anemia
Amount:	$208,138
Investigator:	Neelam Giri, MD, MBBS, National Cancer Institute, Rockville, Maryland
Title:	Studies of Immune Function in Patients with Fanconi Anemia
Amount:	$157,388
Investigator:	Markus Grompe, MD, Oregon Health & Science University, Portland, Oregon
Title:	iPS Cells from Fanconi Anemia Fibroblasts
Amount:	$53,082
Investigators:	Nick Lakin, PhD and Annette Medhurst, PhD, St. Peter's College, Oxford University, Oxford, United Kingdom
Title:	Defining the Molecular Function of FA Proteins during S-Phase (Year 2)
Amount:	$100,149
Investigators:	Majlinda Lako, PhD, Lyle Armstrong, PhD, and Christopher Mathew, PhD, Institute of Human Genetics, Newcastle University, Newcastle upon Tyne, United Kingdom
Title:	Using iPSC Technology to Understand Early Haematopoietic Development in FA Patients
Amount:	$47,000
Investigator:	Susan Mallery, DDS, PhD, Ohio State University, Columbus, Ohio
Title:	Mucoadhesive Patch Delivery of Fenretinide and Berry Anthocyanins for Oral Cancer Chemoprevention
Amount:	$100,000
Investigator:	Susan Olson, PhD, Oregon Health & Science University, Portland, Oregon
Title:	Pathophysiology and Treatment of Fanconi Anemia
Amount:	$55,000
Investigator:	Jakub Tolar, MD, PhD, University of Minnesota, Minneapolis, Minnesota
Title:	Correction of Human Fanconi Anemia Induced Pluripotent Cells by Homologous Recombination
Amount:	$125,000
Investigator:	Susanne Wells, PhD, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio
Title:	HPV Replication and Transformation in FA Squamous Cell Carcinomas
Amount:	$200,000
Investigators:	Stephen C. West, PhD and Andrew Deans, PhD, Cancer Research UK, South Mimms, United Kingdom
Title:	Coordination of the Fanconi Anemia and Bloom's Syndrome Complexes by FANCM
Amount:	$139,250

Family Fundraising Efforts

From January 1 through August 31, 2009, FA families raised $598,802 for Fanconi anemia research. The Fund also received donations of $2,302 through the United Way and $10,138 through the Combined Federal Campaign, for a combined total of $611,242. We extend our sincere thanks to all FA families who worked so hard to raise these much-needed funds. We are so grateful to all of you for your help.

As you know, the challenge will continue until we find a cure for Fanconi anemia. Our mutual fundraising goal this year is $1.5 million. Members of our staff are eager to help you with your fundraising efforts—especially now, during the holiday season.

$100,000 and Up

Ken and Jeanne Atkinson
Dave and Lynn Frohnmayer
Glen Shearer and Peggy Padden

$25,000 to $49,999

Peter and Tara Himmelreich
Kevin and Lorraine McQueen

$15,000 to $24,999

Kerrie Brannock
John and Kim Connelly
Todd and Kristin Levine

$10,000 to $14,999

Ed and Janice Duffy
Kevin and Katie Rogers

$5,000 to $9,999

Yavin Atzmon and Sharon Harari
Andrew and Jennifer Gough
Brian Horrigan and Amy Levine
Charles and Katy Hull
Adam and Olivia Mindle

$1,000 to $4,999

Andrew and Vicki Athens
Mark and Linda Baumiller
Chris and Jennifer Branov
Donald and Danielle Burkin
David and Kim Chew
Donna DellaRatta
Pat and Mary DiMarino
Doreen Flynn
Alan and Rachel Grossman
Owen Hall and Margaret Kasting
Beth and Jeff Janock
Christie and Randy Kelley
Shaid and Melvina Khan
Steve and Jennifer Klimkiewicz
Joseph Konikowski
Lynette Lowrimore
Deane Marchbein and Stuart Cohen
Dan and Nikki McCarthy
Tyler Morrison and Rachel Altmann
Kevin and Lorraine O'Connor
Derek and Ginger Persson
Peter and Janice Pless
Pedro and Marina Ravelo
Bob and Andrea Sacks
Bryan and Karen Siebenthal
William and Mary Underriner

Up to $999

John and Audrey Barrow
James and Tracy Biby
Randy and Nancy Bloxom
Jeffrey and Donna Boggs
Matt and Lisa Buglehall
Patti Carter
David and Paula Ceresa
Jeanette Clark
Daniel Conde
Brad and LeaAnn Curry
Dottie Day
Richard Day
Charles and Dahne Deeks
Mark De Groot and Hanneke Takkenberg
John and Wendy Delzell
Mike Dennis and Ginger Eggers
James and Carol Dillon
Antonino and Marie DiMercurio
Brian and Jennifer Dorman
Gene and Lynn Eddy
Sharon Ellis
Ezat and Laila Faizyar
Justin and Britteny Ferrin
David and Mary Ann Fiaschetti
Nanette Vannostran Foster
Susan Gannon
Gary and Melody Ganz
Lisa and Brian Gillott
Pat and Maria Gleason
Maria and Josh Godwin
Beatriz Goris
Mitchell and Tirzah Haik
Roger and Eleanor Herman
Shane and Colleen Irvin
John and Karilyn Kelson
Kayla Lackey
Peg LeRoux
Tanner and Jessica Lindsay
Eric and Beth Losekamp
Bill and Jackie Lucarell
Steve and Allison McClay
Charles and Cecelia Meloling
Jim and Holly Mirenda
Sydney and Betsy Moore
John and Betty Mozisek
Jack and Lisa Nash
Jack and Tammy Neal
Robert and Mary Nori
Fred and Nancy Nunes
Lori Peterson
John and Dianne Ploetz
Michael and Kay Proctor
Lynn and Shirley Quilici
Mario and Yolanda Ramirez
Lester and Phylis Resh
Paul and Rena Rice
Jan and Leonard Riley
Mark Ritchie and Lisa Mingo
Les and Nancy Ross
Lynn and Rick Sablosky
Erik and Lori Salo
Richard and Dolores Satterlee
Sharon Saunders
Bill and Connie Schenone
Thomas and Brenda Seiford
Tamara Stephens
Daniel Terryah
Mark and Susan Trager
Steve and Melissa Turner
Tom and Kathy Uno
Mike and Beth Vangel
Joe and Wendy Vitiritto
Marc and Sandi Weiner
Kim and Michael Williams
Sean and Kristin Young

How You Can Help

Your donations have helped move this fatal disease from an orphaned status in 1989 to a disease with treatments that now buy precious time for FA patients. As the genetic basis of Fanconi anemia continues to be deciphered, your donations are also having an impact on the lives of millions in the general population. We continue to move to the mainstream of scientific interest. To help us in this fight, consider these ways to donate:

Gifts to celebrate an occasion: If you are celebrating a birth, a birthday, an anniversary, a graduation, a marriage or other event, consider asking that donations be made to the Fund in lieu of a gift.

Gifts to commemorate a loved one: Families who have lost a loved one may ask that a donation to the FA Research Fund be made in their memory. The Fund has received many thousands of dollars from caring people who have commemorated loved ones in this way.

Bequests: If you are preparing or reviewing your *Last Will and Testament*, consider making a bequest to the Fund.

Matching Gifts: Many employers match the charitable gift of an employee. Ask if employers have taken this initiative to encourage philanthropy. This is an excellent way to double your donation.

Gifts of Appreciated Property: Donors who have property that has gained greatly in value (stock, vacation homes, art items, etc.) can avoid tax liabilities and provide enormous support by donating this property to the Fund. Please contact us for advice and suggestions.

Sales on eBay or Purchases through iGive: If you sell an item on eBay, you can designate that all or a portion of the proceeds be given to the Fund through their non-profit MissionFish program [see www.missionfish.org]. You can also donate to the Fund by shopping online through iGive [www.igive.com].

United Way or Combined Federal Campaign: If you work for an organization that participates in either of these campaigns, consider making a donation and asking your colleagues to do the same.

Donations Online: You can donate via the *PayPal* or *Network for Good* buttons in the *Donations* section of our web page (www.fanconi.org).

Donations by Telephone: Call us at (541) 687-4658 or toll free at 888-FANCONI.

Donations by Mail: 1801 Willamette Street, Suite 200, Eugene, OR 97401.

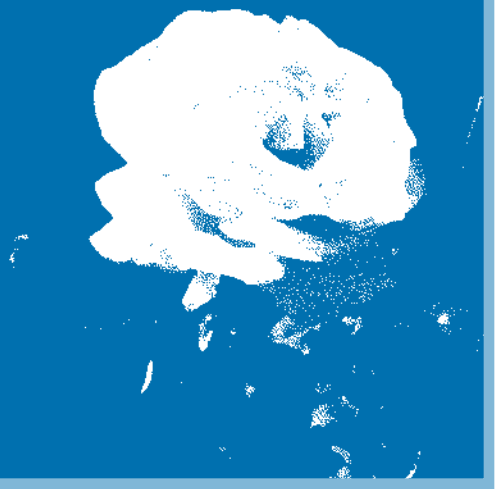
In Loving Memory

Katie Terryah
1/28/85 ~ 6/3/09

Karisma Khan
3/19/02 ~ 7/25/09

Dylan Moore
9/18/01 ~ 7/26/09

Dianna Vannostran
3/12/98 ~ 9/1/09



Climbing Mount Washington for FA Research

continued from page 19

go through and looks back on the transplant with joy. Just like Baylor, I pushed through to the end. It's amazing how a three-foot person can be such an inspiration to anyone with whom he comes into contact!

I am so thankful to have had this opportunity to help raise critical funds for FARF. I want to thank Kevin and Lorraine McQueen and Bill and Jennifer McCorey for organizing Climb for a Cure and for inviting me to participate. Through this effort, we raised almost $23,000 for FA research! ◆

The Twenty-second Annual

Fanconi Anemia Scientific Symposium

October 21–24, 2010

Marriott City Center Hotel
Minneapolis, Minnesota

"A Dream is a Wish Your Heart Makes"

continued from page 10

New York, I met Justin. Justin has been, without a doubt, the best thing about the city. He has helped me to realize and accomplish what I want to do. With his help, I created a web site that is dedicated to raising awareness for cord blood preservation, featuring stories about how it helped to save my life and the latest medical breakthroughs involving cord blood. My motto is, "Everyone deserves a chance to dream, and they deserve to know that cord blood can help make that possible." I am currently writing a book in the hope of raising awareness of cord blood worldwide.

I am extremely blessed in many ways, but mostly because I have a loving and supportive family. I wake up every day and know that if it were not for them, my life would not be what it is now. There will be **things** in life that'll make you happy, **times** in life you will never forget, but it is the **people** in your life who will **always** matter the most! Never give up, anything is possible, and it all starts with a dream!

To learn more about my family's story and the lifesaving benefits of cord blood, please check out my web site at www.nataliecurry.com. ◆

PhRMA
New Medicines. New Hope.®

The Fund would like to extend its thanks to PhRMA for its generous support of the printing costs for this newsletter.

Fanconi Anemia RESEARCH FUND, INC.

1801 Willamette St., #200
Eugene, OR 97401
phone: (541) 687-4658
(888) FANCONI (USA only)
FAX: (541) 687-0548
e-mail: info@fanconi.org
web site: www.fanconi.org